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CHALLENGES AND RECOMMENDATIONS TOWARDS A NATIONAL SYSTEM FOR PATIENT TRACKING

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CHALLENGES AND RECOMMENDATIONS TOWARDS A NATIONAL SYSTEM FOR PATIENT TRACKING

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ABSTRACT

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The United States is often exposed to disasters as a result of everything from terrorist activities to hurricanes. Such disasters have required both inter- and intra-State evacuations, sometimes requiring Federal oversight. Once such disaster resulted in the relocation of thousands of patients.[1] While recent policy changes at the Federal level have yielded improvements in patient tracking evacuation processes, much more is expected.[2,3] Patient tracking efforts have been fragmented, resulting in failure to adequately track patients out of the disaster zone through the continuum of care through re-entry post disaster.[4] Current efforts to collaborate on a synchronized National effort are disparate and are not sufficiently addressed or funded at the Federal level.

This paper examines the necessity in developing a comprehensive National system with Federal oversight for patient tracking. Such a system should have the capability to track special medical needs patients as well as those patients requiring evacuation from medical facilities during both inter- and intra-State evacuations. Recommendations are provided to assist the Department of Health & Human Services

create an azimuth towards a unified objective of patient accountability. A policy strategy is proposed and a methodology suggested.

CHALLENGES AND RECOMMENDATIONS TOWARDS A NATIONAL SYSTEM FOR PATIENT TRACKING

Former Secretary of Defense Donald Rumsfeld famously proclaimed *"you go to war with the Army you have. They're not the Army you might want or wish to have at a later time."*[5] The same axiom can be applied to contemporary disaster response – the ideal processes that we want are not necessarily in place, but the government will respond to the next domestic disaster with the processes in place at the time. This applies to governments at the local, State or Federal level and includes those processes and procedures necessary to potentially move patients and medical needs populations from a disaster zone and across State boundaries, however cumbersome or dysfunctional those processes may be. Such movements require a consistent and ready methodology to track those individuals throughout the continuum of care by the first responders, family members, and those State and Federal entities that manage entitlements and compensations.

Increased scrutiny following the terror attacks of 911 and the major Hurricanes Katrina, Rita, Ike and Gustav suggest that with each passing disaster, more is arguably expected from a demanding public.[6] With the catastrophic events and subsequent medical evacuations resulting from Hurricanes Katrina and Rita receding from memory, the urgency to establish medical evacuation protocols for these populations has also receded. There are generally two categories of medical needs persons who require evacuation in these situations – those patients in medical treatment facilities requiring care and those with special medical needs such as those receiving home care. Both types could be captured under an overarching patient tracking system. The fact that

2009 was fortunately a mild hurricane season that did not generate any federally monitored evacuations of these populations probably contributed to slowed progress in the development of a system. Current efforts to track patients and medical needs persons evacuated from a domestic disaster site are disjointed and disparate.

Why a System is Necessary

While hurricanes along the Gulf Coast in recent years have resulted in the evacuation of medical treatment facilities and special medical needs populations, other phenomena also create conditions where medical evacuations of people on short notice may be necessary for their own safety. These conditions may result from other natural causes, such as flooding, ice storms, and wild fires or they may be the result of terrorist activities, city-wide blackouts, or any number of man-made events that potentially impact the capability of facilities to continue to care for patients or medical needs populations. Not surprisingly, some of these events may result in an immediate need to evacuate persons from a disaster area – sometimes across State, local or tribal lines. It can also be expected that a number of these personnel will require medical care throughout an evacuation, potentially through more than one medical encounter along the way. While many Agencies and organizations seek to address some of these challenges, components of the problem require conformity, cooperation and collaboration to achieve success on a National effort. Understandably, this is an even greater challenge when Federal policy delineates differing evacuation responsibilities for patients versus special medical needs persons. Further examination of the challenges associated with implementing a National system for patient tracking can be

accomplished through the closer scrutiny of two major program components: policy and process.

It is important to keep in mind the difficulty in tracking an individual through space and through a continuum of care, often involving multiple medical assets, multiple organizations and multiple personnel. Any patient tracking system requires a method to identify that same individual through multiple steps along the evacuation and care continuums including entry at point of origin, staging facilities, enroute (ground ambulance, air, bus, train) assets, reception facilities and onward to a wide variety of care facilities and then back again once conditions of both the patient and the disaster zone have sufficiently recovered to facilitate reentry. Information on each individual must be accessible by a multitude of personnel inside and outside of the disaster zone during and after the disaster. Understandably, any overarching strategy must therefore include commonality and uniformity in the terminology associated with the evacuated persons, mechanisms of access, and basic architectural data systems. Efforts to achieve this coordinated system, to date, have not achieved the desired result.[7,8]

The Federal Role

The role of the Federal response in disasters is to shore up State and local capabilities where those are exceeded. The over-arching Federal policy that establishes this mechanism of response is laid out in the National Response Framework (NRF), last updated in January 2008. This Framework "is a guide to how the Nation conducts all-hazards response. It is built upon scalable, flexible, and adaptable coordinating structures to align key roles and responsibilities across the Nation, linking all levels of government, nongovernmental organizations, and the private sector. It is

intended to capture specific authorities and best practices for managing incidents that range from the serious but purely local, to large-scale terrorist attacks or catastrophic natural disasters."[9]

During a response, Emergency Support Functions (ESFs) are a critical mechanism to coordinate functional capabilities and resources provided by Federal departments and agencies, along with certain private-sector and nongovernmental organizations."[10] "The Federal Government and many State governments organize their resources and capabilities … under 15 ESFs. ESFs align categories of resources and provide strategic objectives for their use. These ESFs provide the structure for coordinating Federal interagency support for a Federal response to an incident. They are also mechanisms for grouping functions most frequently used to provide Federal support to State and local organizations requiring that support."[11] The ESFs identify primary and supporting agencies to help clarify who has responsibility for executing the functions of the ESF. It is through these ESFs designated within the NRF where we find the roles and responsibilities of the two ESFs with responsibility for evacuation: the Department of Health and Human Services (DHHS) and the Department of Homeland Security (DHS).

DHHS has responsibility for ESF 8 – Public Health and Medical Services. According to the Public Health and Medical Services Annex to the NRF, "ESF 8 coordinates the Federal response in support of emergency triage and pre-hospital treatment, *patient tracking*, and distribution."[12] Similarly, ESF 6 - Mass Care, Emergency Assistance, Housing, and Human Services, which is the responsibility of DHS, includes support to evacuations (including registration and tracking of evacuees)

as a requisite capability. DHS' responsibility is largely mass evacuation efforts versus the sub-population of patient evacuation. However they are responsible for the evacuation of persons with special medical needs. Additionally, ESF 6 is responsible for familial reunification, which should be a goal for an effective patient tracking system. Even though DHS has responsibilities for general population evacuation, DHHS is the designated lead agency for *all* patient evacuation tracking within the NRF and may be asked to support DHS in its responsibilities for patients with special needs.

The NRF was designed to correct observed response issues following events such as Hurricane Katrina. However, there have been subsequent reviews to indicate that some policy areas, like the consolidated patient tracking efforts during disasters, have not yielded the desired result. One GAO report stated "real-world events have shown that incomplete policies and plans may adversely impact response efforts. For example, the White House and GAO concluded that incomplete policies and plans contributed to the lack of clarity in leadership roles and responsibilities in the response to Hurricane Katrina. This problem resulted in disjointed efforts by emergency responders that may have caused increased losses of life and property."[13] While this GAO report broadly covered response policies and plans in general, the lack of an overarching patient tracking policy is a component of that effort that requires further attention.

Another GAO report identified "coordination challenges" and "attributed … problems to coordination difficulties between emergency management and other agencies."[14] Most revealing, the Nationwide Plan Review, a Congressional requirement to review and assess the status of catastrophic and evacuation planning in all States

and 75 of the Nation's largest urban areas, found "current catastrophic planning is unsystematic and not linked within a national planning system. This is incompatible with 21st century homeland security challenges, and reflects a systemic problem: outmoded planning processes, products, and tools are primary contributors to the inadequacy of catastrophic planning."[15] The Review specifically addresses inadequate progress in establishing viable patient tracking processes, stating "there are interoperability issues with various tracking systems that response agencies (e.g. EMS, hospital, and public health) use."[16]

All of these reports indicate the government's efforts to address such a critical component of the NRF – a viable patient tracking system – are burdened by policy constraints, lack of leadership and disjointed approaches to addressing these challenges. While DHS has no responsibility for patient tracking specified in the NRF, their movement role for special medical needs populations infers a responsibility to track and maintain accountability of those individuals as well. Neither DHHS nor DHS, however, has published approved policy guidance addressing how to collaboratively achieve a National system for patient tracking. The NRF has not yielded the synchronized and cooperative efforts necessary when addressing patient evacuation or movement.

Organizational Structures to Support a System

Improvements to the operational structures of DHHS and DHS may improve collaborative efforts in the movement of both hospitalized patients and medical needs persons. DHS, through the Federal Emergency Management Agency (FEMA), and DHHS cooperatively assist State and local governments through regional offices.

FEMA is the Agency that is charged with "supporting our citizens and first responders to ensure that as a nation we work together to build, sustain, and improve our capability to prepare for, protect against, respond to, recover from, and mitigate all hazards."[17] FEMA manages efforts through ten geographic regions across the United States. Each of these ten regions then coordinates with the individual States within their designated regions. DHHS mirrors these ten regions with their own regional offices in order to promote collaboration at the regional level. However, these FEMA and DHHS regional offices generally require the establishment of joint field offices during response operations to effectively manage the collaboration of Federal assistance those areas require. An examination of this structure and the roles and functions of these offices is required.

One of the systems DHHS utilizes to augment medical response is the National Disaster Medical System (NDMS), the "federally coordinated system that augments the Nation's medical response capability. The overall purpose of the NDMS is to supplement an integrated National medical response capability for assisting State and local authorities in dealing with the medical impacts of major peacetime disasters and to provide support to the military and the Department of Veterans Affairs (VA) medical systems in caring for casualties evacuated back to the U.S. from overseas armed conventional conflicts."[18] NDMS operates through 72 Federal Coordinating Centers (FCCs) throughout the United States. Currently, 32 of these FCCs are controlled by the Department of Defense (DoD) and 40 by the Department of Veterans Affairs.[19]

The roles and functions of the FEMA regional offices, the DHHS regional offices and the FCCs should be examined for consolidation and to better synchronize efforts

and create efficiencies among these organizations. For example, the FCCs are "generally not responsible for coordinating the evacuation of patients *out* of an affected area."[20] This is considered a State responsibility, so clear guidance is not spelled out for use by either NDMS or FEMA personnel on how to assist in the management of intra-State patient evacuation.

Likewise, no specific guidance was in place following Hurricane Katrina for the return of those patients once evacuated. The result was that a Federal contract was necessary to manage the return of evacuated patients. Because guidance was not in place at the regional level, the contract was managed out of DHHS Headquarters in Washington D.C.[21] While processes have since been put in place to assist in the management of returning patients, these actions should be codified in policy and performed at the regional level. Merging the regional offices of FEMA and DHHS and integrating the roles and functions of the FCCs on a full-time basis potentially provides a more coordinated effort in addressing the increasingly challenging processes involved in disaster response in general, and patient tracking and movement in particular.

Currently, FCCs are activated when needed and inactivated when no longer needed. The integration of the FCC functions into the combined regional offices of FEMA and DHHS could then be augmented with additional capability available full-time, such as patient regulation functions. Additionally, full-time capability could then allow these offices to assist State and local governments through disaster response exercise participation, assistance in writing and implementing State and local disaster response plans, policy implementation, and assistance with other State and local organizations in

disaster response capability improvements. Further examination of FCC ownership and viability logically follows but will not be addressed here.[22]

Department of Health and Human Services' Efforts

Published guidance or policy is also necessary. While DHHS leadership agrees that returning evacuated patients post-disaster is their responsibility, it is not specifically identified as a specified subtask in the most current Hurricane Playbook[23]. Although the published FCC Guide addresses the issue, the DHHS CONOP has not yet been approved that includes the return leg as a component of the plans. Whereas the majority of patients evacuated from a disaster zone would arguably be evacuated using mass transport means (aircraft, bus), the more likely scenario is that returning patients would be transported back in smaller increments – even individually, as patient condition and accepting facility times and conditions permit. This is precisely what occurred post-Katrina.[24] Much happens to patients between when they are initially evacuated and when they are potentially returned. Such actions include their release from medical care, where they are then free to return on their own accord, or possibly death. Perhaps the medical condition worsens, which may indicate they remain in the facility where they were evacuated to or they return to the disaster location, but to a different, more specialized facility. Approved published guidance is necessary to ensure the DHHS position is integrated in subsequent patient movement and tracking collaborations.

In efforts to establish some foundational concepts, the Agency for Healthcare Research and Quality (AHRQ) published "*Recommendations for a National Mass Patient and Evacuee Movement, Regulating, and Tracking System"* to assist in [the]

development of a system that could be used during a mass casualty or evacuation event to locate, track, and regulate patients and evacuees."[25] "The AHRQ is the lead Federal agency charged with improving the quality, safety, efficiency, and effectiveness of health care for all Americans. As one of 12 agencies within the DHHS, AHRQ supports health services research that will improve the quality of health care and promote evidence-based decision-making."[26] This document has since become the guiding document for the DHHS regarding patient tracking efforts – even though no departmental published policy guidance exists establishing it as Federal policy. In terms of goals and objectives for a National system, those established by the AHRQ provide an excellent framework within which to continue work. These goals and objectives could be further codified into policy for the Department as a whole and then distributed to subordinate and inter-Agencies. Still, there remains a lack of urgency in doing so and in creating a National system for patient tracking.

One model that could be mirrored in order to achieve momentum in accomplishing a National patient tracking effort is that used by the DHHS in implementing the National Health Security Strategy (NHSS). The Pandemic and All-Hazards Preparedness Act (PAHPA) in 2006 directed the Department to submit a product to the Congress by the end of the year in 2009. In order to accomplish this, a project lead was appointed, an Inter-Agency Policy Committee was formed, and daily meetings occurred to advance the agenda. Contractors were hired for the sole purpose of guiding development, production and implementation. That same sense of urgency must be applied to this effort. Through this model, much progress can be made with National patient tracking efforts.

In their lead capacity under the NRF, the Department should move to consolidate efforts to implement a National patient tracking system through other processes already resident within DHHS. This could be accomplished through a well-articulated policy document, restructured implementation procedures (both written and through the recommended re-organizational efforts previously addressed), and in further progress towards the patient tracking application or process itself. Much work has already been done in each of these areas throughout DHHS and nothing suggests having to start over. However, if real progress is to be made, there needs to be more of a synchronized and concerted effort to pull these disparate components together.

The Department of Health and Human Services' Strategic Plan, most recently published in 2007, offers a variety of information technology recommendations in efforts to solve long-standing problems associated with public health following disasters, including those involving patient evacuation.[27] While the Plan suggests improving response preparedness efforts through the information technology realm, specific mention of a patient tracking system is not included in the document. This, although numerous oversight products have identified patient tracking efforts as inadequate. Within DHHS, the Assistant Secretary for Preparedness and Response (ASPR) is currently developing the operational document to codify patient movement actions.

Information Technology Solutions

Any National system requires the interoperability of existing and newly developed electronic systems. Therefore, commonality of terms of reference, standardized data fields and architectural standards are mandatory. Per the AHRQ, "an ideal National System would update location and health status information of patients and evacuees at

any location where they are treated, housed, sheltered, or transported, including overnight facilities, locations where patients and evacuees board or get off vehicles, or other temporary gathering points. This information would be made available to authorized persons with responsibility for housing, transporting, or treating patients and evacuees, both at the person-level (e.g., to determine where a specific person is or has been and to alert health care professionals and emergency responders at reception centers to the medical condition of patients and evacuees who will be arriving shortly) and at the aggregate-level (e.g., to determine the number of patients or evacuees, by health status, at various locations within a county, a multi-county region, a State, a multi-State area, or nationwide). An ideal National system would also: contain timely location and health status information that is updated as soon as possible after the patient or evacuee arrives at or leaves one of these locations; include comprehensive medical information, so health care professionals can provide appropriate medical care to patients and evacuees; ensure patient and evacuee confidentiality; and adhere to all Federal privacy regulations such as the Health Insurance Portability and Accountability Act (HIPAA), and guard against stalkers or other predators; support patient/evacuee movement and regulating decisions by providing information on the availability of medical and transportation resources in both an affected area and unaffected areas where patients and evacuees could potentially be transported; and support decision making, monitoring, and reporting for emergency response and recovery."[28]

Any patient tracking solution will clearly be heavily reliant on information technology. DHHS has recognized this and tackled the problem in the Disaster Medical Information System (DMIS) Strategic Program Plan, an information technology plan

generated by the NDMS Chief Medical Officer (CMO). Clearly, the ability to track a patient through the continuum of care is essential to any effort to provide quality care and accountability thus enabling integration and improvements as specified in the DMIS Strategic Program Plan. However, "the transfer of patient medical information and tracking is inconsistent at best during large events and not easily shared between local, state and federal responders."[29] The system itself described in the DMIS Plan and the requirements as currently stated in the AHRQ document are considered baseline requirements in DHHS' patient tracking application efforts.

To date, the NDMS Chief Medical Officer has been leading the information technology efforts in establishing many information systems for the NDMS, of which a patient tracking application is just one. I suggest the CMO is not the appropriate lead for these efforts. As the senior medical officer within the NDMS, his duties should remain focused on the medical aspects of the NDMS. The result of his current involvement in the information technology realm is that once he becomes heavily involved in medical issues such as the Haiti relief efforts, progress in the information technology projects he leads slow or cease.

The DMIS Strategic Plan, penned by the CMO, describes a system inclusive of triage, tracking and regulation sub-components. Combining all of these goals into a single system initially may prove to be self-defeating because there are so many subordinate variations and processes to integrate in order to achieve one final overarching solution encompassing all three of these goals. Each of these three subcomponents is on their own timeline for maturation and implementation. Waiting for one of these goals to mature prohibits completion of the entire system. I strongly

suggest focusing primarily on the patient tracking piece first, as the initial component of a much larger effort, with the capability to expand as other elements become more standardized and accepted.

As State and local organizations begin to adopt the policies and procedures implemented, confidence builds and private industry should follow. Additionally, as the system continues to mature, additive improvements to the system can be made. Incentives for State and local buy-in could include the capability to support their State-to-State mutual aid agreements. With common architecture systems, States could more easily coordinate intra-state patient evacuations and Federal involvement, when warranted, could occur literally with the flip of a switch to gain access to the State's data. Federal access to State data would only be necessary and utilized when Federal assistance is requested to support evacuations or for integrating Federal and State response operations. State and Federal capability to track both patients and special medical needs persons is also critical when considering both accountability and compensation and entitlements. These combined attributes may prove incentive enough for State buy-in to common data architecture.

The effort to achieve a standard architecture should be led by the information technology office, rather than by the CMO. The National Health Information Technology Office within DHHS has been cited as making progress in "comprehensive management of medical information and its secure exchange"[30] which is so vital to a National patient tracking effort. Further information technology development to integrate electronic patient tracking with electronic medical records must be synchronized with other National Health Information Network (NHIN) efforts.

"The NHIN is built upon a core set of capabilities to enable nationwide information exchange encompassing a diverse set of organizations, technologies and approaches. Core capabilities include:

- Ability to find and retrieve healthcare information within and between health information exchanges and other organizations;
- Ability to deliver a summarized patient record to support patient care and to support the patient's health;
- Ability to support consumer preferences regarding the exchange of his or her information, including the ability to choose not to participate in the NHIN;
- Support secure information exchange;
- Support of a common trust agreement that establishes the obligations and assurances to which all NHIN participants agree;
- Ability to match patients to their data without a national patient identifier;
- Support of harmonized standards, which have been developed by voluntary consensus standards bodies for exchange of health information among all such entities and networks.

The core capabilities of the NHIN establish an interoperable infrastructure among distinct networks and systems that allows for different approaches and implementations, while ensuring secure information exchange as needed for patient care and population health."[31] These are all vital components of any information technology solution for a National system for patient tracking because the premise is that any National system will require integration of systems already in place. Most importantly, the critical NHIN components of establishing a common patient identification system and securing patient

information are important complements to patient tracking efforts. Thus the system should be a component of and integrated with, not distinct from, the NHIN. The challenges associated with synchronizing the various electronic systems already in place at the State and local levels can be mitigated by conforming to NHIN parameters at the Federal level from the outset.

Patient Tracking Applications

Some local and State jurisdictions already employ electronic personnel tracking methodologies that could be expanded to include patient tracking requirements. Texas, for example, has employed the Special Needs Evacuation Tracking System (SNETS).[32] While not specifically designed for patient tracking, the system uses barcode readers, wristbands and a centralized database to track evacuees (including medical evacuees). Any State-issued identification card (such as a driver's license) can be swiped to input critical basic information fields. The National system should capitalize on systems such as SNETS already in place by State and local organizations. For example, the National application would 'pull' the requisite tracking information from within the SNETS database. Thus the SNETS database feeds the federally integrated application with requisite data while simultaneously reducing data-input requirements on the ground. In this manner, a National system is truly a network of the various State and local electronic systems already in use. New systems established in those areas currently without, built with common architecture soft and hardware, would be added to the network as they come on line. For these areas, access to the National system should be offered with a public software application. Equipment could be obtained through

grants. Training on both equipment and software could be performed through a train the trainer program, again managed regionally.

Such capabilities as described here have already been demonstrated through applications used in the military. While the military system is a relatively closed one, arguably without the same privacy concerns as a more 'public' system might have, recent applications have integrated DoD and VA records with civilian electronic medical records, expanding the capability of the military's systems to be more conducive to a public type application. These efforts make the VA system "capable of easily exchanging health records with other EMRs and organizations using standards built for the Nationwide Health Information Network (NHIN)."[33] Pilot programs in San Diego in Fall of 2009 have been successful in exchanging critical patient information between DoD, VA and Kaiser Permanente electronic systems utilizing NHIN standards. Additional pilot tests are scheduled for Chicago and the Tidewater area of Virginia. "The pilot's objective is to provide the capability to exchange health information using the NHIN between DoD, VA and private sector within a defined data set and a defined set of patients in a production environment. The pilot is scheduled to begin by 31 July 2010 and continue through 1 December 2010."[34] It must be emphasized that without the requisite guiding principles, definitions and policy, a truly interoperable tracking system will not be possible.

One such electronic tracking application now widely used by the military is the Joint Patient Tracking Application, or JPTA. JPTA was initially developed by the military for strategically tracking patients once they left the combat zone in Iraq. The system is not a database per se, but works by 'pulling' information from a variety of other data

sources and then 'displaying' the information in what appears to the user as a single database. In fact, the information is pulled from multiple databases and is reliant upon other feeder systems for information. JPTA has since been expanded and is now in use by the VA, where it is known as the Veteran's Tracking Application, or VTA.[35] The VTA has been so successful throughout the VA that it has been integrated into the Administration's overarching information technology suite, the Veteran's Health Information Systems and Technology Architecture (VistA).[36]

According to the application's initial designer, the JPTA application could be modified and employed in a similar manner as the VTA in order retrieve information from State and local systems to gain access to information regarding evacuated patients or special needs persons.[37] The DoD has since shared the data code for JPTA with DHHS (with modifications) to facilitate tracking and electronic health record efforts. DHHS has renamed their variant the Joint Patient Assessment & Tracking System (JPATS) and is considering its use as an open code for use by the public. Once this is accomplished, State and local organizations will have a ready-made option for 'plugging' into a National application for patient tracking, improving efficiencies and reducing errors. The use of the JPATS has already been incorporated into the DMIS Strategy within ASPR and I recommend the ASPR seek recognition of the DMIS Strategy by the NHIN.[38]

Another relevant application recently developed and now in widespread use throughout Iraq and Afghanistan is CIDNE, the Combined Information Data Network Exchange, developed by Intelligent Software Solutions (ISS). ISS is a contracted company whose software is used extensively by U.S. Central Command (CENTCOM).

CIDNE is described on the company's website as "the CENTCOM directed reporting tool within Iraq and Afghanistan. CIDNE serves the primary bridge between disparate communities who might not otherwise share data by providing a standardized reporting framework across intelligence and operations disciplines. This common framework allows structured operational and intelligence information to be shared vertically and horizontally as part of flexible, user-defined workflow processes that collect, correlate, aggregate and expose information as part of the end-user's individual information lifecycle requirements."[39] In essence, CIDNE is an off-the-shelf application that could be employed today at the most basic local level. Users complete a report through an interface and higher echelons then have the capability to query all date horizontally and vertically across the system. This capability does not exist in JPTA in its current form. Optionally, CIDNE could be employed at the grass-roots level as a web-based portal with no requirement to access other feeder systems.

CIDNE was employed in Iraq to track coalition patients. The goal was to automate the daily medical evacuation reporting by the various units to enhance the fidelity and integrity of the data for use in operational planning and trauma analysis. The end result, achieved in short order, was an automated solution that tracks the patient from point of pickup through the continuum of care, simply by each user along the way making additions to the base report when necessary. Interested persons with access to the system can log in via web portal and find the location of their Soldier at any time after the evacuating unit completes the report. CIDNE functions as a fusion system where each user of the system provides additive information and situational awareness along the continuum as the evacuated individual moves through the system.

Each encounter provides additional information on the evacuated person. With the additive capabilities of wrist bands like those used in Texas, bar-coding, wireless transmission and centralized repositories of information, one can easily see how a system such as this could provide critical capability for both inter- and intra-State use.

Both the JPTA and CIDNE applications work by 'fusing' information from disparate sources and integrating the data into user-defined information. This is precisely the model required for a National system for patient tracking – one born of fused disparate applications (some of which are already in place). For systems such as JPTA, CIDNE or JPATS to work effectively to that end, 'like' or common data fields and architecture need to be identified throughout any subsystems that would be included in the National patient tracking network. The basic electronic architectural elements need to be standardized across all levels of use. To avoid starting from scratch, we can again refer to the AHRQ document and use it as guidance for establishing the basic data fields required for patient and medical needs population tracking. Subsequent information technology efforts through the NHIN to standardize electronic architecture could ensure unity of effort.

Lessons Learned From JPTA & CIDNE

While the AHRQ provides a much-needed direction for civilian DMIS development, there are some lessons learned from the development of JPTA and the CIDNE tracking system that may be helpful to identify here. First, the AHRQ document proposes a system only to be activated or turned on when necessary. The military has found success in the 'train as we fight' mantra, ensuring that methods necessary at crunch time are embedded in Soldiers' responses and therefore become instinctive.

The same applies here. It is difficult to believe that a National system could be established and effectively 'turned on' when necessary with the expectation that the users are fully trained and capable of adequately utilizing the system.

Any system arguably needs to be one that is used in the day-to-day operations at the grass roots level so that no additional training or intervention is necessary once a disaster occurs. Processes and procedures could be used daily by local EMS organizations for patient movements and honed to the point where they become second nature. Once a disaster occurs, actions for use should be reflexive versus turning on a system and trying to remember how to use it.

This is a known issue already identified in the DMIS Strategic Program Plan, which states "utilization of patient tracking systems and electronic medical record keeping is often associated with a reduction in tactical-level productivity."[40] Further, "the extent to which the patient tracking and EMR systems are perceived by tactical level operators to be easily useable and providing direct, tangible benefit to the delivery of patient transport and patient care services determines whether these systems are utilized during disasters at all."[41] In other words, the utilization of any system at the most critical point along the continuum of care must be instinctive and second nature and this will arguably not be efficiently achieved by a system that is only turned on sometime leading up to the event when evacuations are already underway. Federal access to the system need only occur when State and local organizations request Federal assistance to facilitate intra-State patient movement or to coordinate Federal response. The information could already be resident within the system at this point, but the Federal managers would access it only when necessary. (There would be no need

for Federal access during routine day-to-day operations at the local EMS level, although the local organizations would still be utilizing the system day-to-day). States could feasibly control Federal access to their data. Proficiency of Federal users of the system could be maintained by online or periodic refresher training.

Second, use of zip codes in patient identification criteria is not practical. Zip codes do not necessarily reflect where an individual is from geographically (and thus needs to go back to for reentry). The zip code, as suggested by the AHRQ, merely indicates where the individual entered the evacuation tracking chain. Thus, if someone was looking for a patient who had been evacuated, they may not know the zip code where the individual was first uploaded to the system, so any reference to a zip code becomes irrelevant from that perspective. Additionally, it is likely that first responders (i.e. ambulance drivers assisting from a different geographic area under the National Ambulance Contract) won't know the local zip codes. Rather, they respond to a site and deliver the patient to the air hub for further evacuation. An option used in Iraq is to use the first and last initials, followed by the last 4 digits of the social security number, the time of day, and then the date (e.g. XY1234170512MAR2010). If initials or social security numbers are unknown at the point of entry, pre-allocated sequential alpha-numeric numbers for each evacuation platform or location could be used instead.

A permanent system would also eliminate the requirement for up front training when a disaster is imminent since all emergency responders would already be trained on the system. Again, using the Ambulance Contract example, ambulances will be arriving on scenes from other jurisdictions or States where they must be able to quickly integrate into the local evacuation/patient movement process without significant delay

due to re-training or learning the local systems. As the DMIS Strategic Plan adequately states, “even when additional resources arrive and are operational they may be fully engaged in patient care and/or transport with a diminished capability to manage additional requirements of data entry and information management.”[42]

Third, an option to consider is to establish a web-site where medical needs persons or their families can go online and input their information voluntarily. A similar system is used by FEMA for general population evacuees, but, again, only once a disaster strikes. The National Emergency Family Registry and Locator System (NEFRLS)[43] is ‘turned-on’ when necessary and provides an on-line resource for family members to try and locate other family members ‘lost’ during the evacuation process. This system could be converted to a proactive system, where personal and family information is pre-loaded especially in disaster prone regions of the country, potentially as part of a CONOPs or playbook for that particular region or pending disaster. While this may initially only be feasible for those special medical needs individuals, once medical facilities network with the National System, it could be used for patient evacuation as well.

Conceivably, those patients requiring evacuation from hospital facilities may have their information ‘pulled’ from the electronic hospital admission records. This would require the medical facilities to share patient information with the National system. These arrangements would have to be made locally or regionally and the coordination efforts would be the responsibility of those respective regional FEMA/DHHS offices. There will always be folks who will still have to be input into a tracking system on-site but using a pre-enrollment system could eventually ease workload during the disaster.

Identification information can be tied to driver's license numbers, voter registration numbers, social security administration information, hospital records or internal revenue service databases, and would have to be determined locally. While it is doubtful we could expect 100% pre-enrollment in any area, any pre-enrollment at all reduces workload at the time of disaster response.

Of critical importance, any approved National level system or policy should not dictate to State and local officials what electronic systems they use. Rather, Federal policy should define the electronic data architecture and standards. The State and local governments and organizations should provide the information systems they want the National tracking system to tap into and then assist in establishing those conduits of information. This will require separate information system application 'reach-in' (only when requested) for each of the State and local jurisdictions and will have to be worked locally. For example, Texas could come back to DHHS with consent for the National architecture reach-in access to their SNETS system. DHHS could then provide the staffing assistance and expertise to synchronize that access.

Fourth, the issue of patient identification is a huge challenge that must be overcome if any National system can be realized. DHS, as the lead agency for mass evacuation and the parent Agency for FEMA, is heavily immersed in trying to solve this problem. In the past, efforts to create a National Identification Card or some other form of identification have met with fierce resistance.[44] However, any effort to establish a patient identification system must be synchronized with the DHS effort and not be a standalone identification system. Both DHS and DHHS (among many others) must be able to view the information contained within the electronic contents of the identification.

Conversely, any DHS solution must support the NHIN core capability of matching patients to their data without a national patient identifier.

Fifth, is simply the robustness of the tracking application. It must remain minimalist enough to remain practical. For example, while an electronic triage indicator may be a later improvement and can continue in parallel development, it does not necessarily need to be a part of the initial application if we are concerned with just tracking an individual. The re-evaluation of patients prior to movement may prove to be problematic so the patient tracking system will still work with little or no information regarding patient condition. To include triage and evacuation precedence indicators in JPTA, for example, would require a great deal more effort to expand because these fields are not resident in other feeder applications that JPTA requires. An application such as CIDNE could include these fields in the basic architecture of the code or they could be added relatively easily at the user level later on. The initial goal must be simply to track the patient with as little information as is required to effectively do so.

The establishment of goals, strategy and unity of effort must be managed with the expectations of the State and local jurisdictions in mind. It will be inherently difficult to get States to come on board with a National effort if they have spent time and money implementing their own mechanisms. However, if the National effort supports the State and local efforts and expands their intra-State capability, one might anticipate additional buy-in. This may also be approached from the perspective that information sharing would benefit State-to-State mutual aid agreements, with the Federal access to the system only when required in a support role. States should realize the advantages of

having a common system for intra-State operations as well considering its potential use in determining qualification for compensation and entitlements.

I also suggest that a grass-roots campaign be organized to seed the patient tracking campaign at local and State levels. Key to any successful nationwide program is knowing what's necessary in order to introduce local systems and where to get funding for those systems. The AHRQ has begun work in this area by identifying some of the systems currently in use[45]. By providing State and local assistance, we can incentivize the use of the systems offered to the public. Those local jurisdictions that have already implemented tracking applications should not be penalized for doing so, rather target those areas without systems in place for Federal grants for hardware and software tools to assist in linking them together to establish the National tracking network. These grants could be used for digitizing processes at the local levels where they don't already exist and may include assistance in implementing electronic health records, electronic training on evacuation and accountability procedures, exercise participation and sustainment, and equipment purchases. There is a great deal of grant money available through the health information technology realm that State and local organizations could tap into in order to get these information technology systems off the ground.[46,47] Additional monies under the American Recovery and Reinvestment Act (ARRA) are also available.[48] By directing regional and local engagement on these projects and funding the appropriate expertise at these levels, a bottoms up network of information exchange systems can be established to provide the architecture required of a National system.

Recommendations

History has indicated that concerted progress towards a viable patient tracking system with a clear obtainable goal is not forthcoming without executive guidance. I recommend efforts be codified and achieved through a series of working groups, similar to a process in use today. Currently used by the National Security Staff, the Inter-Agency Policy Committee (IPC) is a representative model that may be of value in completing these efforts. (While a Disaster Recovery Working Group has already been designated by the White House, this group's focus is on post-disaster processes.[49] Patient movement and the tracking efforts are intended for use prior to, during as well as post-disaster.)

A high-level committee established to address patient movement and tracking specifically accomplishes several things. First, it signifies the process as vital to the health of the country and demonstrates a commitment to move the processes forward to implementation. Secondly, it clearly establishes a hierarchy that can be used when internal processes get bogged down. Thirdly, it designates the stakeholders that need to be involved, critical in this process as some Agencies have been less involved than they probably should be. With DHHS the designated lead, other members should include the DoD, DHS, and the VA at a minimum. All will have vital roles in not only policy formulation and effective integration but also in the system's implementation. Finally, an organization external to DHHS can then establish a timeline for completion and drive the implementation of the system. With the many unforecasted public health demands on DHHS that disrupt any routine progress, an external driver may assist in driving the project to completion. Subcommittees could then tackle various aspects of

the overall effort. Each of these recommended subcommittees are discussed next, along with some recommended responsibilities of each.

DHHS understands their role in patient movement and patient tracking under ESF 8 and has made progress towards defining the scope of the problem. Among other things, they have established a Senior Leader Council on Patient Movement (SLCPM), bringing together Assistant Secretary level authorities involved in the patient movement realm in efforts to resolve coordination challenges between the various departments. Some of the Departments involved in the SLCPM include DHHS, DHS, DoD and the VA. This Council should be re-designated as the over-arching inter-Agency committee and chartered to accomplish synchronized efforts through subcommittees to address several key components of the initiative: patient movement itself, the roles and functions of the regional field offices, the development of the information technology tracking application and the implementation of the system.

The Patient Movement Working Group currently run by the Office of Preparedness and Emergency Operations (OPEO) within ASPR should be designated as a subcommittee to the IPC. Current efforts by this group focus on establishing CONOPs for patient movement surrounding disasters from a generalized perspective. The fundamental work occurring within this group is critical in standardizing nomenclature, processes and procedures and expectations across the stakeholder population. This work should continue under a directed timeline established by the IPC.

A second subcommittee should be established in order to evaluate the re-organization of the regional offices of DHHS and FEMA and integration of the FCC functions. Co-chaired by FEMA and ASPR-OPEO, this subcommittee should examine

the employment, organization and functions of the regional offices and the FCCs and their relationships with the various stakeholders. The group should investigate the removal of DoD and VA from FCC ownership in order to streamline communications and unified policy implementation guidance from DHS and DHHS. Any consolidated organization should be operational full time and include patient movement and regulation functions at the regional level. This would provide a single point of entry at these levels for patient movement and tracking management and oversight. It would also streamline communications from top to bottom. This group would also be responsible for updating the operational guidance currently in use by the FCCs and the regional offices.

A subcommittee for tracking application development should be chaired by the Office of the National Coordinator for Health Information Technology (ONC). One of the roles of the ONC is to "develop, maintain and direct the implementation of HHS' strategic plan to guide the nationwide implementation of interoperable health information technology…"[50] This subgroup should include the CMO for NDMS in an advisory role, but not as the lead, allowing him instead to function primarily in his medical role. This subcommittee should assist in refining the DMIS Strategy originally written by the CMO, assist in merging the document with an overall management plan and drive the technological effort currently underway. This effort should also include refinement of the selected application (JPATS or CIDNE variant) to ensure it conforms to the NHIN standard. Additionally, the application should have interoperability with the military's patient tracking applications but not be reliant upon them. To facilitate this progress, DHHS should hire a Program Manager for this effort who is familiar with the

Military Health System (MHS) Information Technology systems currently in use. This hiring action has been discussed among DHHS stakeholders who all agree in concept.

When DoD assets are utilized for patient evacuation, they expect to utilize their own patient tracking system, the Transportation Command's (TRANSCOM) Command and Control Evacuation System (TRAC2ES). ESF 8 states, "DoD is the only recognized Federal partner responsible for regulating and tracking patients transported on DoD assets to appropriate treatment facilities."[51] Thus, any National system must be capable of integrating with the TRAC2ES system. However, with the heavy deployment of DoD assets in today's environment, reliance on the military's assets, including TRAC2ES, may not be wise. Organizations must have access to systems that can be utilized without necessarily having the military involved. Thus, any integrated National system must be able to interact with TRAC2ES when the military is involved in an operation, and function just as well without it when they are not. Both JPTA and CIDNE possess this capability. Remember, the approach outlined here supposes a fully operational tracking system functioning year-round, not just following a disaster event.

An additional subcommittee should be charged with the grass-roots implementation of the application. This subcommittee should largely deal with the funding requirements and grant programs to enable digitizing patient movement processes at the local level. Initially, a thorough assessment needs to be made as to what local regions already possess in regard to electronic patient tracking capability and then target those areas without. While the AHRQ has performed work in this regard[52], the next step is determining what existing systems States have and whether they are willing to share the information such as the Texas SNETS and VA examples used earlier. This group

should then assist with the grant programs to support the establishment and implementation of the system in those areas currently without linkable systems. While State and local organizations already operating or paying for their own systems may initially balk at grants going to these other areas, they must be made aware that the systems they are using will assist in both their inter- and intra-State patient movement and evacuation processes. Grants could be used to assist those areas with systems in place to make their systems inter-operable at no cost to the State or local organizations.

Within DHHS, more priority and urgency must be given to policy development and those efforts currently underway must continue until such designations of subcommittees and leads outlined above can occur. The development of policy is absolutely critical in the evolution of any National system because of the vast differences involved in terminology, information technology systems architecture, privacy issues and human identification methods used by the various stakeholders, just to name a few. The DHHS Secretary, as part of this effort, should direct in writing an interim co-lead effort between the ASPR and the ONC. As the system largely relies on an information technology solution, it is critical to have the technical side of the system developed in coordination with (as opposed to after) the policy guidance. This relationship would help ensure that as the application for the system develops, compliance and integration with the NHIN would be assured. A side benefit would be the utilization of the information dissemination channels informing State and local users of both the information technology and patient movement realms.

Further, there is a presumption that the DMIS Strategy Plan and the AHRQ document are official Department guidance, but there is no implementing directive

stating so. Refinement of these documents and their merging into one program management plan would then help guide further efforts. By establishing a program management plan, DHHS would be better positioned to ensure that the policies and plans are developed and integrated with each other and the national preparedness system as envisioned by law and presidential directive.[53] Additionally, stakeholders would more likely accept policy and application products if completed and disseminated as official products.

DHHS should seek a budget earmark for this effort. I recommend a system that is fully implemented and used daily at the local and intra-State level, with Federal access employed when that level of support is necessary. While the initial earmark should be used to get the system up and running, Federal dollars need also be sought for sustainment. Currently, separate agencies are pulling money from other internal programs in efforts to piece together components of a viable patient tracking type system. For example, the NDMS is currently using money designated for the Hospital Preparedness Program to fund progress in patient tracking applications[54]. A budgeted earmark is needed to hasten progress and to establish a Federal commitment to the project to include long-term sustainability. This would also allow the agencies to continue to fund the programs internally with the money originally designated for those programs. An estimated $1 – $1.5 million dollars would get the basic program off the ground, provided the legal aspects of sharing data and NHIN requirements can be met. Further analysis conducted by the subcommittees previously discussed could help frame sustainment dollar projections.

Although separate from the patient tracking policy and application implementation, the DHHS should make an effort to ensure that their electronic data library is accessible to State and local organizations. There has been much work accomplished in and among the various sections of DHHS, but there does not appear to be a central, publicized site available for State and local organizations to reference the documents necessary for sharing among organizational elements (OPEO, FEMA, and NDMS) and stakeholders.

Conclusion

There are a lot of well-meaning staff working hard to institute a viable patient tracking system. Unfortunately, their efforts are largely uncoordinated, unguided and unfunded. These efforts to date have been deliberate, but need to be more aggressive and methodical. With a concerted effort by the DHHS, the lead agency for patient tracking according to the NRF, advocated by an IPC type process, these efforts can be synchronized and a National system could be operational within months. The technology clearly exists to do so. This effort would require the same determination and focus as the Department's recent efforts in implementing their National Health Security Strategy. Unfortunately, if the problem is not addressed in this fashion, we will soon find ourselves facing another domestic disaster without an appropriate system in place. We already know that "during a disaster, data exists on patients….. Effective response in times of disaster requires that such data be readily accessible and linked to support tracking needs. We lack the capability to exchange meaningful data across systems to facilitate evacuation holistically."[55] An 80% solution fielded today is better than a 95% solution that never gets off the ground.

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